# Masters of Medicine (Mmed) Dissertation in Ophthalmology

# "Barriers to Cataract Surgery in Africa: A Systematic Review"



**Shaheer Aboobaker**

**Paul Courtright (Supervisor)**

**DECLARATION**

I, *Shaheer Aboobaker*, hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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Signature: Shaheer Aboobaker

Date: 15th February 2016

# Table of Contents

## Systematic Review Protocol

**Barriers to Cataract Surgery in Africa: A systematic review**

Shaheer Aboobaker; Paul Courtright

### Objective of the Review

To collate information pertaining to barriers to cataract surgery in Africa

### Background

According to WHO estimates, approximately 39 million people around the world are blind. Approximately 6 million of these are from Africa, which is an approximate 1% of the population, of which 50% are due to cataract.[1] In view of this burden, the WHO and IAPB started Vision 2020 in 1999. One of the targets of Vision 2020 is to increase the cataract surgical rate (CSR) in Africa, which is currently estimated to be between 200-400 operations/million/year to 2000 operations/million/year by the year 2020.[2] There are many challenges to overcome if we are to achieve this goal. Aside from the limited numbers of surgeons available and the lack of availability of resources, one of the biggest hurdles are barriers to access of surgical services to the population.

Information currently available stems from Rapid Assessment of Avoidable Blindness (RAAB) studies done in Africa. A Rapid Assessment of Avoidable Blindness (RAAB) is a survey methodology to report on the prevalence and causes of blindness within a specified area or population. It focuses on the prevalence of avoidable causes of blindness, namely cataract, refractive error,

trachoma and onchocerciasis. With regard to cataract it also attempts to report on prevalence of cataract, cataract surgical coverage (CSC), barriers to uptake of cataract surgery and visual outcomes after cataract surgery.

Many RAAB's have been conducted throughout Africa, however, a systematic review of all this data has not yet been done. This review aims to collate this data and assess trends identified as it relates to barriers to cataract surgery.

## Inclusion criteria

### Types of studies

The following types of studies will be eligible for inclusion:

- Systematic reviews
- Qualitative and quantitative studies of barriers pertaining to Africa
- RAAB studies done in Africa

## Methods

### Search Strategy

The following electronic databases will be searched for relevant studies:

- MEDLINE/PubMed
- Google Scholar

The following search terms will be combined:

"barriers, cataract, Africa, cataract surgery, cataract surgical coverage (CSC), and Rapid Assessment of Avoidable Blindness (RAAB)"

The search will be limited to English studies from 1999 onwards.

**Study selection**

Stage 1: Identified studies will be assessed for relevance to the topic. Those studies considered not relevant will be excluded.

Stage 2: Full text/papers will be reviewed for all studies meeting the inclusion criteria.

**Data extraction**

Quantitative data will be extracted from relevant studies and entered electronically using MS Excel and tabulated for use in the final article.

Qualitative data will be summarised and tabulated using MS Word and may be included in the final discussion where key points may show insight into the extent of the problem.

**Data synthesis**

This type of review should not require data synthesis. Findings will be collated and compared to one another and trends evaluated. Quantitative findings will be summarised and presented in tabulated form and may assist in the basis of the discussion.

## References

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**Abstract**

*Background*

Cataract remains the leading cause of blindness in Africa. We sought to review the available literature relating to barriers to cataract surgery in Africa.

*Methods*

A review of the literature was undertaken using PubMed and Google Scholar using the search terms "barriers, cataract, Africa, cataract surgery, cataract surgical coverage (CSC), and Rapid Assessment of Avoidable Blindness (RAAB)". The review covered the period 1999-2014.

*Results*

In RAABs, barriers related to awareness and access were more commonly reported than acceptance, while non-RAAB studies reported cost as the most commonly reported barrier. The few qualitative studies tended to report community and family dynamics with regard to barriers to cataract surgery. CSC was reported as lower in females in 88.2% of the studies.

*Conclusion*

Studies of barriers to cataract surgery give variable responses. This may be due to the study context but also may be due to the type of data collection. It is likely that qualitative data will give a deeper understanding of the complex social, family, community, financial and gender issues relating to barriers to uptake of cataract surgery in Africa.

## Introduction

According to WHO, 39 million people around the world are blind and cataract remains the leading cause of blindness in low and middle incomes countries.[1] The WHO and the International Agency for the Prevention of Blindness (IAPB) launched the VISION 2020: Right to Sight initiative in 1999 to reduce the burden of avoidable blindness and cataract was one of the key conditions targeted.

Since then, many surveys have been published highlighting the magnitude of cataract related vision loss in Africa. That said, Africa remains the continent with the lowest cataract surgical rate (CSR), defined as the number of cataract surgeries done per million population per year. There has been considerable research on the barriers to use of existing cataract surgical services in Africa and we sought to compile and review the available literature of barriers to cataract surgery in Africa to identify key themes. This information may be of assistance to programmes aiming to increase the uptake of cataract surgical services.

## Method

A review of the available literature was conducted using PubMed and Google Scholar. Search terms used included the following: "barriers, cataract, Africa, cataract surgery, cataract surgical coverage (CSC), and Rapid Assessment of Avoidable Blindness (RAAB)". The search was limited to articles published between 1999 and the present (April 2014), a 15 year period.

The references within articles also were reviewed to identify other articles that may not have been identified by the search terms.

In reporting on the barriers in the studies, we have attempted to use the perspective that a patient with cataract would have; a patient first must know that there is a problem, what the problem is, and what to do about the problem (knowledge and awareness). Once aware of the problem then the patient needs to address the logistical steps needed to use the service. This includes distance (and transport) to the service, fees to be paid to use the service, needing an escort to use the service, and being told by service providers that this is the appropriate time to use the service (or told to wait). Generally, it is the role of the eye care service to make the service accessible to the population by reducing the problems associated with transport, setting prices within the capacity to pay of the population, and to offer the service when patients need and want the service. The final step is to make sure that the patient and the family will accept the service. Poor acceptance can be due to fear of surgery (some of which may be due to poor quality service and some due to incorrect assumptions regarding surgery), to no perceived need, to a perception that advanced age means that surgery is unnecessary, or that to be blind is due to "God's will".

Finally, as female gender is a recognized risk factor for lower utilization of cataract surgical services, all quantitative surveys of cataract surgical coverage were reviewed to assess any gender differences.

**Results**

In total, 86 articles were identified using the search terms. Among these 86 articles, there were 12 that were RAABs.[2-13] In addition to the RAABs there were

10 articles on barriers to use of cataract surgical services that were quantitative in design[14-23] and 5 articles that were qualitative in design.[23,26-29]

Although the RAAB survey includes questions on barriers to cataract surgery not all publications report these findings. Among the 12 published RAABs barriers data was only available from 9. Among these publications the picture is quite mixed (Table 1), characteristics related to awareness and access being more commonly reported than characteristics of acceptance.

The other (non-RAAB) surveys of barriers were undertaken in a number of different population groups, not all of which were population based. (Table 2) While there is a considerable heterogeneity of findings, cost (both direct and indirect) was the most commonly reported barrier in six of eight studies.

Finally, there were 5 qualitative studies of barriers (Table 3). These studies were carried out in Tanzania and Kenya. These studies suggest that complex emotional and social interactions exists within the family network that influence the mobilization of financial resources to use cataract surgery. Elderly patients place the financial needs of their children ahead of their own and do not wish to be seen as a burden. Uptake of surgery is also affected by the perceived need for surgery. Economically active men had a higher perceived need than women, who tended to suffer their disability in silence. Despite the difficulty in accessing funds, these studies found that patients were willing to pay for cataract surgery. This willingness increased when knowledge of the actual cost of surgery and trust in that service were improved. Cost was found to be a convenient

explanation that is unchallenged by health care workers when asked about reasons for not undergoing cataract surgery. The Kenyan study found that patients with poorer visual acuity were only slightly more likely to accept cataract surgery while lower quality of life scores were consistently associated with increased uptake of cataract surgery.

There were 19 surveys providing information on CSC. Among these surveys, 17 presented findings for both men and women. In 15 (88.2%) of these surveys the CSC among men was higher than among women; overall, with all surveys included the average difference between male CSC and female CSC was 9.42%. (Table 4)

**Discussion**

To adequately carry out the literature review, four sets of publication types required collection and compilation. Each of them offers different perspectives on the topic of barriers to cataract surgery in Africa and review of the different perspectives informs the discussion on barriers to cataract surgery in this and other settings. The variable findings in this review may be due to a number of factors, first being the context in which the study was undertaken. The type of study may also have contributed to the variable findings.

RAABs have the advantage of being standardized and population based; a significant disadvantage however is the fidelity of the findings. In the RAAB the question on barriers is asked of all people with a cataract causing vision loss of 6/18 or worse in one or both eyes. There is good evidence[27] that, because the

question "Why have you not had surgery?" can be very sensitive, people may provide an answer that will not cause embarrassment or be challenged by the interviewer (generally an eye care provider). In this case obtaining an accurate response may be quite difficult. This appears to be particularly true with the response "cost of surgery"; researchers in Tanzania found that, among those reporting cost as the primary barrier, when cost was removed as a barrier still over 77% of patients still refused surgery.[27]

Combining findings from people with bilateral and unilateral cataract and combining people with blinding cataract (<3/60) with those having a visually impairing cataract (6/24-6/60), as RAAB does, also weakens the interpretation of the findings; it is likely that the barriers are different according to vision and laterality.

The second set of data on barriers comes from a mix of population-based surveys or institution based surveys. Collection of data varies in these settings and some of the same strengths and weaknesses found in RAABs are evident in other population based surveys.

Due to the sensitive nature of questioning people about reasons they have not undergone surgery, qualitative data collection is likely to be the most valuable approach. Current qualitative literature on the topic remains limited to a few settings and findings from these settings may not be generalizable elsewhere in Africa.

Finally, the last set of findings from the literature review, gender differences in cataract surgical coverage, provides strong evidence of continuing gender-specific barriers which women face in most countries in Africa. This work has been summarized globally, first in 2002[33] and later in 2008[34]. Similar to global findings, Africa specific data shows that in almost 90% of surveys reporting CSC data for males and females a lower CSC was reported for females. Gender inequity was also reflected in the qualitative studies, the reasons for this may lie in gender-defined social roles within the community. Women may have less access to money and there is less of a perceived need for improved vision due to their roles in the household and community.[35] According to a study in Tanzania, men express their need for better sight more strongly than women. Women tended to hide their disability and suffer through adversity due to fear of being seen as a burden and felt shame in asking their children for support. Some elderly cataract patients may see more benefit in ignoring their need for sight compared to a socially negotiated process of being perceived as "ill" to mobilise resources.[28]

All of these studies illustrate that barriers exist both in the community and within the health care system. A study from South Africa explored the lack of hospital or management commitment to increase CSR; issues identified included insufficient theatre time; nursing staff unfamiliar with high volume cataract surgery, and surgeons performing non-surgical related work (screening, refractions, administration).[36] Similar health system based issues were reported in Ethiopia[19] and some studies[37] have highlighted the changes made to the health system and the subsequent increase in CSR. The assumption in these settings is

that the health system changes addressed specific barriers that were noted through formative research.

While "cost" is a commonly reported barrier in many surveys evidence suggests that making surgery free-of-charge does not significantly increase use of cataract surgery in Africa.[26,28] Included in the definition of "cost" is the fee charged for surgery (direct cost) and the indirect costs needed to use the service (e.g., transport, escort, meals and accommodation). Without substantial government investment in cataract surgery, offering free cataract surgical services in Africa is not sustainable. Different fee schedules have been adopted in some hospitals; critically, base fees need to be set within the capacity of the population to pay. In many settings this calculation is based on 80% of households and waiver systems are used for those too poor to pay at all.[27] However, cost may be hiding a deeper and more complex issue. While capacity to pay can be calculated, the role of the family in decision making and the willingness to pay can be more difficult to assess. In 2005 when counseled on the actual cost of surgery, 20% of patients, who initially stated price as a reason for not having surgery, subsequently returned with funds.[27] These funds were obtained from family members; the willingness of patients to pay for cataract surgery is linked to the highest perceived amount of financial support elderly patients feel they can ask from their children and relatives.[26]

Reducing direct costs may be achieved by increasing productivity and by implementing a tiered payment system to subsidize poorer patients. Some centres have attempted to package direct and indirect costs (including transport

and medication) into one all encompassing fee. The indirect costs may be reduced by "outreach teams" going into the communities and screening and transporting a busload of cataract patients back to the base hospital for their surgery. These outreach teams are closely linked to the hospital and provide staff qualified to make good clinical decisions in the field to prevent unnecessary referrals into the hospital. They provide a "patient friendly" one stop service and the site of the camp is chosen based on population distribution and is well advertised and occurs at a regular interval.[37]

While none of the studies directly addressed the question of trust in achieving a good outcome, it is likely to remain a significant barrier given the often poor cataract surgical outcomes reported from population based studies. Poor outcomes create distrust in the service and fear of having surgery. These legitimate concerns would also harm cost recovery efforts as the perceived value of cataract surgery would be reduced. Bias in reporting probably accounts for the lack of information on the impact of poor outcomes on acceptance of cataract surgery.

In summary, while there are numerous studies of barriers to use of cataract surgical services, the tendency to tackle the question from a quantitative perspective may not be ideal. Quantitative data may not reveal the true issues preventing uptake of surgery, either because of a lack of willingness of respondents to criticize health providers or to embarrass themselves or others. To this end, qualitative work is likely to provide far deeper understanding of some of the complex social, family, financial, community and gender interactions

in these settings. Further work to understand the role of poor outcomes to uptake and to understand how families make decisions regarding seeking care would be helpful. The high CSC found in some settings in South Africa, Libya, and Kenya suggest that many barriers to surgery can be overcome; there is no single approach however and efforts need to be multi-system and long term.

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Table 1: Findings from RAABs: Percentage of those not having surgery reporting the reason for not accepting surgery

| Country (reference) | Awareness | | Access | | | | | Acceptance | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | Knowledge | Unaware | Transport | Service unavailable | Lack of escort | Cost | Awaiting maturation | No need | Fear | God's wish | Old Age |
| South Africa (2) | 50 | | | | | | | 25 | 25 | | |
| Libya (3) | 22.9 | | | | 2.1 | 4.2 | 29.2 | 6.3 | 6.3 | 16.7 | |
| Cameroon (4) | | 17 | | | | 40 | 8 | 10 | | | |
| Cameroon (5) | | 33.3 | | | | 30.1 | | 9.6 | | | |
| Eritrea (6) | | | | | 17 | 30 | 18 | 10 | | | |
| Kenya (7) | 34.1 | | | | 12.2 | 24.4 | | | | | |
| Malawi (8) | 11.8 | | 13.2 | | 22.1 | | | 23.5 | | | |
| Rwanda (9) | 52 | | | 16 | 8 | 16 | | | | | |
| Zambia (10) | 48.1 | | | 10.7 | 4.5 | 3.8 | 8.6 | 3.1 | 2.8 | 15.5 | |
| Tanzania* (11) | | | | | | | | | | | |
| Burundi* (12) | | | | | | | | | | | |
| Madagascar* (13) | | | | | | | | | | | |

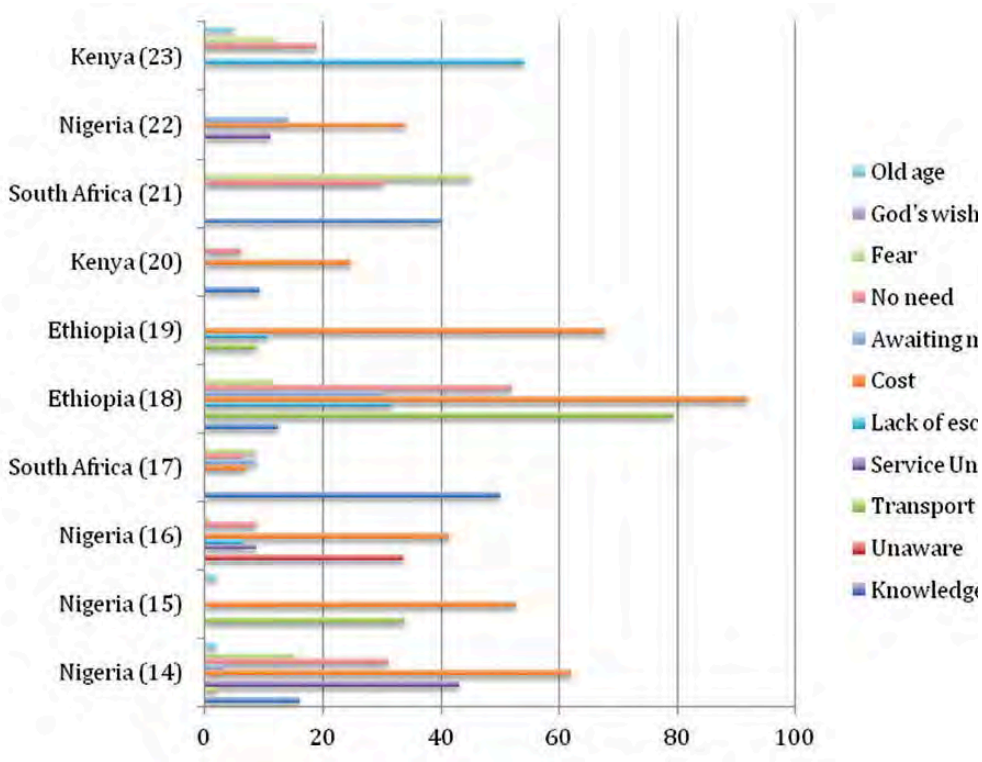
* No data on barriers reported

Table 2: Findings from other surveys of cataract barriers

| Country (reference) | Survey population | Awareness | | Access | | | | | | Acceptance | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Knowledge | Unaware | Transport | Service unavailable | Lack of escort | Cost | Awaiting maturation | No need | Fear | God's wish | Old Age |
| Nigeria (14) | Leprosy patients in leprosy villages * | 16 | | 2 | 43 | | 62 | 3 | 31 | 15 | | |
| Nigeria (15) | >50 years in three rural communities | | | 33.8 | | | 52.8 | | | | | |
| Nigeria (16) | >50 years Plateau state | | 33.6 | | 8.6 | 6.3 | 41.4 | | 8.6 | 0.8 | | |
| South Africa (17) | Pension pay point | 50 | | | | | 7 | 8.7 | 6.4 | 8.7 | | |
| Ethiopia (18) | Outreach clinics * | 12.3 | | 79.4 | | 31.5 | 91.8 | 30.1 | 52 | 11.6 | | 37 |
| Ethiopia (19) | >40 years Gurage zone | | | 8.7 | | 10.4 | 67.8 | | | | | |
| Kenya (20) | Random Kibera slum dwellers >2yrs | 9.3 | | | | | 24.8 | | 6.2 | | | |
| South Africa (21) | >40 years random cluster Zulu | 40 | | | | | | | 30 | 45 | | |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Nigeria (22) | Outreach screening <6/18 | 11 | 34 | 14 | | | | |
| Kenya (23) | Outreach screening <6/18 | 54 | | | 19 | 12 | | 7 |

* Numbers add up to more than 100% and respondents could respond to more than one barrier.




Graph 1: Findings from other surveys of cataract barriers in graph form

Table 3

Findings from qualitative studies of barriers to cataract surgery

| Study site (reference) | Main findings | Secondary findings |
|---|---|---|
| Kenya (23) | Lack of knowledge of cataract surgery can lead to fear and rumours affecting uptake | High quality cataract surgery is paramount to increasing uptake of cataract services |
| Tanzania (26) | The amounts patients were willing to pay was much less than the cost of service | Willingness to pay was linked to knowledge of the service and its cost as well as trust in the service |
| Tanzania (27) | Cost may be a convenient explanation that is unchallenged by health care workers | Some patients who initially reported cost as a barrier managed to access funds to cover the cost of surgery |
| Tanzania (28) | The acquisition of financial resources for cataract surgery requires the involvement and assistance of other family members. This creates complex emotional and social dynamics that prevent elders from accessing these resources due to fears of burdening their offspring or assuming a sick role. | Uptake of surgery is influenced by the perceived need for sight and the social and cultural context. Men express a stronger need for surgery than women; women are more willing to suffer in silence rather than burden their children. |
| Kenya (29) | Lower quality of life scores were associated with an increased uptake of cataract surgery | Men were twice as likely to accept cataract surgery than women: Patients with poor visual acuity only slightly more likely to accept cataract surgery |

Table 4: Cataract surgical coverage by person in men and women in Africa

| Country (reference) | **CSC <3/60 (M)** | **CSC <3/60 (F)** | **Difference between men and women** |
|---|---|---|---|
| Nigeria[24] | 5.3% | 2.6% | +2.7 |
| South Africa[2] | 96% | 96% | 0 |
| Libya[3] | 95.9% | 94.8% | +1.1 |
| Nigeria[14] | 47.4% | 30.6% | +16.8 |
| Eritrea[6] | 70.9% | 64.9% | +6.0 |
| Nigeria[25] | 29.4% | 21.7% | +7.7 |
| Nigeria[16] | 60.5% | 48% | +12.5 |
| Kenya[7] | 78.3% | 77.6% | +0.7 |
| Zambia[10] | 72.1% | 65% | +7.1 |
| Nigeria[30] | 37.7% | 21.2% | +16.5 |
| Rwanda[9] | 64.3% | 36.4% | +27.9 |
| Nigeria[31] | 4.9% | 3.6% | +1.3 |
| Malawi[8] | 61.5% | 29.5% | +32.0 |
| Tanzania[11] | 73% | 66.6% | +6.4 |
| Burundi[12] | 16.7% | 23.5% | -6.8 |
| Madagascar[13] | 50% | 41.7% | +8.3 |
| Nigeria[32] | 51% | 30% | +20 |